

## **ND DUAL SENSORY ADVISORY BOARD MEETING 5/19/15**

**INTRODUCTIONS:** Look at sheet with contact information, any revisions? Joni Andre from Region 1 has retired. I would like to have someone from Region 1 on the Board. Any ideas? *Connie suggested that we consider getting another administrator on the Advisory Board, possibly Shawn Huss from Williston.*

**CENSUS:** Each year, December 1, 2014, census is taken. This year the totals were 32 children who were Deaf-Blind, last year it was 27 students. Only 3 students are reported on the Part B Child counts by the schools as Deaf-Blind. One student from GF will be removed ; one child from West Fargo moved to SD . There are 9 students from Jamestown area, 2 Fargo, 3 West Fargo, 4 Grand Forks, and 5 students from Minot. Only one student reported in the birth – age 3 program. *Project staff are meeting with Early Intervention programs to inform them of the impact of dual sensory impairments on development and emphasize the importance of early identification and referral.*

**NATIONAL CHILD COUNT 2013:** Began in 1986, nearly 30 years of data from State DB Projects and the Pacific Trust territories, Virgin Islands & Puerto Rico. There were 9,454 children and youth reported in 2013 - 552 infants/toddlers and 8,847 ages 3-21. WESTAT PART B reports 1,539 students (3-21) reported on their IEPs as DB in the primary/secondary category.

\*Prevalence of CHARGE increased to 864 kids, #s with Usher Syndrome decreased

\* Cochlear implants increased to 914 compared to 167 in 2005—a five fold increase

\* 43% of children had 4 or more additional disabilities, in 2005 13.1%

\* 26% participate in regular curriculum and statewide assessments

\* 29% of preschoolers are educated in regular EC education settings

\* 75% of students taking state assessments were in regular classrooms some portion of the day

\* # of youth graduating from high school has doubled from 99 to 199 in past 7 yrs

\* 94% live at home in their communities, less than 2% live in private residential facilities

\* 45% of kids on census use some assistive technology

\* Etiology of children who are Deaf-Blind include: 864 children with CHARGE, 270 Usher Syndrome, 1050 Complications of Prematurity, 2345 hereditary disorders, 107 Dandy Walker, 111 Stickler Syndrome, 248 Down Syndrome, 329 CMV, 180 Head Injury, 178 Meningitis, and unknown reasons 1727.

**DEAF-BLIND LIBRARY:** All materials have been moved to the NDVS/SB library. There were about 250 resources that were weeded out and disposed of. There were about 25 new resources purchased this past fall on topics of transition, special education law, cochlear implants, deaf education, audiology and deafblindness. Parents, professionals, teachers, and anyone can check out resources from the library through ODIN system. Any ideas of how to promote the library materials? I write articles about resources in the newsletters for the schools. Emily Stenberg is the NDVS/SB Librarian. *Holly asked if the Dual Sensory Project has a FaceBook page. This is a great social media avenue for families. NDSD and NDVS both have FaceBook pages that are utilized by families. The resources could be discussed on the FaceBook page. Sherri will look into this...great idea!*

**DB INFORMER NEWSLETTER:** The newsletter went out this fall, October 2014, and articles are being collected for the next one in the fall. Half of the newsletters are sent out through email. About 233 are sent out through the mail to EI agencies, SPED units, Anne Carlsen Center and parents and another 180 emailed. About 300 resources mailed out by the Project this year. Over 200 phone calls to the Project per year. Office space is shared with 2 staff from NDSD and 2 staff from NDVS/SB.

**MOODLE NATIONAL DB MODULES:** The Dakota Cohort began May 1 and continues to the end of August. The first 4 modules are being presented-Welcome, Overview of DB, The Sensory System, the Brain and Learning, The Role of the Intervener in Educational Settings & Building Trusted Relationships and Positive Self Image. There are about 22 participants from ND & SD. There are TVI, TOD, Spec ED teachers, interpreters, interveners, paraprofessionals, and one parent participating. There are 3 other ND Professionals that went through the modules on their own. We have participants from Fargo, West Fargo, Grand Forks, Belcourt, Dickinson, Bismarck, Max, Mott, Valley City, Mandan, Aberdeen and Mission SD. These modules will be offered again in the fall and another cohort of the next 4 modules including topics of: Availability for Learning, Understanding Communication Principles, Emergent Communication, and progressing from Non-Symbolic to Symbolic Communication and Complex Language. I am working on ND credit---will receive credit from University of SD this first go around. *Paul talked about the importance of keeping up with other states and providing the necessary support for students in ND. ND is one of the few states that have no certified interveners. Further work needs to be done in this area for ND students who are Deaf-Blind. Holly had talked to Sherri about using the DB*

*modules for her college classes and it is recommended that she talk to Nancy Steele from the National Center to set that up. This information was sent to Holly.*

**ACTIVE LEARNING WORKSHOP:** a two day workshop on Active Learning will be held in Fargo in August. The philosophy behind this approach is that when given the opportunity to learn from one's own active exploration and examination of the environment, the child will achieve skills that become part of his behavior pattern. Any child can learn. This approach was developed over 30 years ago by Dr. Lilly Nielsen from Denmark that focused on establishing motivating learning environments for children with complex needs. Patty Obrzut, an OT from Michigan, will provide a full agenda of training at the Dakota Medical Foundation building, Thursday & Friday, August 13 & 14, 2015. This workshop is open to parents, interpreters, teachers, EI, therapists, and anyothers. Registration fees of \$100 for both days / free to parents who have children with complex needs.

*Ramona talked about the fact that training in this area has not been in the state for many years. She felt this would be valuable for new staff. Paul mentioned that the role the "Little Rooms" have played for children throughout ND has been so important. There was a staff member from NDVS/SB that made the Little Rooms. Jody said that she remembers the Little Room where Eden would explore and play when she was in the Early Intervention Program. They had a Little room in their home for Eden to safely play for sometime. Sherri encouraged everyone to share the information on the workshop. Robin will share the information with the list serves she participates in and the Special Education staff statewide.*

**TA PLANS:** This process was written into the grant that started in 2013. Each parent was interviewed during January & February and we talked about the following needs for each child: education, friendship/social experiences, communication, technology, dreams & aspirations, transition, and employment. Parents were asked what their needs were for school, home or in the community. What they have learned about their child and what they wish they had learned sooner. Goals were written to address the needs for each student and TA Plans were developed for the Outreach staff. Next year the calls will be made in September/October to give more time for the Outreach staff who serve the kids.

The greatest needs as reported by the parents are social opportunities and friendships. A large majority of the parents were sad to report that their children do not have close friends other than those in sporting activities. Technology needs were discussed and there were a number of children who could benefit from the

iCAN CONNECT program from IPAT for technology needs for communication such as iPhones and iPads.

*Linda talked about the needs in the area of social skills and pragmatics for those who are Hearing impaired. The Outreach staff try to get kids together when possible. They recently had a teen meeting by IVN for students across the state. It was a success and they had many students that participated. Paul talked about the same issues that they face with children who are Blind. The social skills are always a challenge and instruction and modeling is needed in that area. They offer camps and Family Weekends to address these areas. Jodi talked about the fact that her daughter has had no concerns in the academic areas but socially she wants her daughter to have friends and healthy relationships for the future.*

Following each TA visit, staff are requested to fill out one sheet regarding the TA consultation listing who they saw, who participated, what they discussed and with whom. This data is documented into the FileMaker Pro database system for each child. There were about 270 consultations reported from last March to the end of February, 2015, on topics such as Braille, communication, routines, sign language, tactual symbols, and calendar systems. There were 3 universal trainings provided and 11 targeted trainings for 11 students on the census within all regions of the state except region 2 & 8. Targeted trainings were provided to students in Carrington, Jamestown, Valley City, West Fargo, Portland, Grand Forks, Williston, Watford City and Devils Lake. These numbers are down compared to previous years. *Documenting visits is a continued concern to be sure that the data is accurate as reported to OSEP.*

**ANNUAL PERFORMANCE REPORT:** Each year the Project has to report what was done for each goal and objective in order to be approved for the next years' grant award of \$65,000. PART B funds of \$40,000 have been given to the Project each year since 2013. Without this supplemental income, the Project would be very limited in the scope of financial assistance and professional development that could be provided! Currently the budget of the Project has about \$57,000 to use by the end of September. Last year, the Project was able to purchase many supplies with the Part B dollars including 4 iPADS, a LCD Projector, a digital camera, a screen, and many adaptive materials/toys.

Highlights of the Project activities included: cross training for staff from NDSD and NDVS/SB; visiting EI Part C programs (western part of state left to do); a new Project brochure was created; 11 targeted trainings with professionals/Respite Care providers/parents ; intensive trainings by two staff once/week at Anne

Carlsen Center; “The Art of Working with Individuals Who are Deaf-Blind with Paul Deeming from MN DB services (35 individuals attended in Fargo from MN, SD & ND); Transition Summit (Fargo) in the fall for Deaf/HOH/DB students/families/professionals. There were 43 participants, 8 students, and 4 parents that attended the two days. Then over 40 interpreters attended a full day training in Moorhead. Over 200 individuals attended the evening deaf-culture comedy event with Keith Wann.

Staff attended the following trainings supported by the Project: PEPNET Summit paid for by PEPNET in Denver, CO and Washington DC, PACER Symposium in June (1 staff), Indicator 13 training by DPI (1 staff), Family support for lodging at Family Weekend in Bismarck and Grand Forks, parents & grandparents to attend the CHARGE Conference in Chicago; family to attend the 4P Conference in Philadelphia, PA, Alexander Graham Bell conference in Orlando, FL (2), Cortical Vision Impairment conference in Omaha, NE (2), Visual Processing Therapy conference in Fargo (2), OSEP Project Director’s meeting in Washington DC, AAC in the Desert conference in Phoenix, AZ (2 staff), O & M conference at Helen Keller National Center in NY, and 1 staff to attend Western Regional EI Conference in New Mexico in September. Upcoming trainings include the DB Summit in Salt Lake City that is required for the Project Director, and the Midwest Deaf Conference in Sioux Falls, SD. In addition, many staff took advantage of the Cortical Vision training was held this fall at NDVS/SB for staff by Beth Ramella—50 attendees, including 2 parents.

The Project continues to work with parents to provide information on trainings available in the area, Family Weekend opportunities, and workshops offered. A transition packet was created for those transitioning from EI to preschool and a packet for those transitioning into postsecondary education/employment or independent living.

PEPNET team houses many transitional materials for Deaf/HOH/DB on the NDSD/Adult Services website. The Project Director is the secretary for the Region 5 Transition Community of Practice that meets monthly. Teen Night Out was established for this group with the help from Joan Karpenko from PathFinder Parent Center. Social experiences are a great need for students who have disabilities and these regional social events have been very successful in Grand Forks and Fargo.

Transition continues to be a great need for students who are Deaf-Blind in ND. A large majority of the students on the census are over the age of 12 and are in

middle school/high school. Families need to be prepared and informed on all the issues surrounding transition. National and regional resources are available and must be shared with families and the professionals who work with the children who are DB. New avenues are being explored to provide access to more information on Deaf-Blindness, including the Open Hands Open Access Modules from the National Center. Parent and families are the constant in student's lives and must be empowered with education and support!!

*Robin asked about the protocol for how to determine who will get trainings paid for by the Project for both parents and professionals. Sherri reported that in the past, parents and professionals would talk to Outreach staff or Sherri about seeking financial support for trainings or conferences and depending upon the current budget, decisions were made. Staff complete training requests through their agencies and then this is discussed with the Project Director and administrator. The Project and Outreach staff have collaborated with other agencies such as the Foundations at NDVS/SB and NDSD/RCDHH and the CHARGE Foundation to help cover expenses when possible.*

*After the meeting, the Fargo participants discussed how to use social media to connect students who are Deaf-Blind in a safe environment. Sherri will talk with other DB projects in July at the DB Summit to see how they are connecting students through social media.*

*Thanks to those who participated in the Advisory Board meeting! I greatly appreciate your input and feel free to contact me anytime by email or phone to give input regarding the Project activities/goals. If I missed anything in the notes, please let me know. I will send these notes out to everyone on the team.*

*Sherri Nelson 5/20/15*